

Washington State Health Care Authority
Health Information Infrastructure Advisory Board (HIIAB)

Health Information Infrastructure Option:
“**Health Information Utility Model**”

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Executive Summary

The HIIAB (the Board) is considering several possible approaches to developing a health information infrastructure for the State of Washington that would provide timely access to high value electronic patient information when and where needed.

The Board has not determined a specific plan or model for creating a statewide health information infrastructure. This draft document describes one proposed approach with a summary of two other models under consideration, known as "The Health Information Utility Model." This draft document will circulate to the Board members and various stakeholders for review and comment as part of the process that will ultimately lead to the development of final recommendations by the Board later in 2006. This is a first draft that resulted from the April 27, 2006 Board work session and will undergo continued refinement. Updates to this work will be posted on the HCA HealthIT and EMR Project web link: <http://www.hca.wa.gov/hit/>

In the "Utility Model" each person would designate an organization of their choice, known as a Medical Record Home, to be the holder of their electronic health record (EHR). Each EHR-based patient record would contain copies of the electronic health information from that institution and any normalized data obtained from participating outside institutions for that person. The Medical Record Home would make an agreed upon set of that data available in a read-only view to medical care providers from non-Medical Record Home participating institutions (via a secure data cache with an internet portal, called for the purpose of this draft an Edge Proxy Server) with the explicit consent of the account holder(patient) or their designee. Whenever new medical information about the person was produced at a participating institution that was not the person's medical record home, the non-Medical Record Home entity would notify the Record Locating Service, which would in turn send a message to the patient's home that new clinical data were available. The patient's Medical Record Home would send a request for the new clinical data to be sent electronically in encrypted format to the Medical Record Home where it would added to the patient's existing clinical record.

Each Medical Record Home would have the option of assessing small fees to their patients for maintaining this system of interoperability if that strategy were consistent with their business model. Each healthcare entity serving as a Medical Record Home would be required to meet established criteria for, security, and backup consistent with current privacy and confidentiality standards.

The record locating service (which could serve the entire state), would be run by a non-profit organization governed by a balanced group of health care stakeholders to include strong representation from consumers. As of yet the mechanism for funding the record locating service has not been determined and will be within the purview of a Finance & Sustainment Sub-Committee.

I. The Problem of Access to Health Information

In today's health care system, each person's medical records are usually scattered among multiple providers and institutions. While each such entity has records about the services they have delivered, no organization currently is responsible for collecting, maintaining, and providing for the timely availability of a person's complete health record.

As greater numbers of clinical facilities implement electronic health records there is an growing opportunity to aggregate key information from different data sets in either one, or small number of locations, at which it is likely to

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be of greatest value to that person and his or her healthcare providers. At the same time there is the opportunity to make the most complete data set in that single location, or small number of locations, visible in real time to other sites where the person may from time to time receive medical care.

The current fragmented state of health information is clearly detrimental to the safety and quality of care, and results in substantial unnecessary costs from duplicative tests and procedures. The Institute of Medicine and others have documented serious problems caused by medical errors, which result in thousands of unnecessary deaths and other adverse outcomes each year. Such errors are rarely due to poor performance by well-trained health care professionals, but rather are a result of a medical care system that does not consistently provide access to the complete and timely information needed to make medical decisions.

II. The Role of Information Technology in Addressing the Problem

There is widespread agreement that converting from paper records used in the health care system to electronic format can save lives, improve the quality of care, and reduce health care costs by providing immediate access to complete electronic patient information *"when and where needed."* There are at least two important components involved in achieving this goal:

First, all the records must be electronic. This means that every doctor's office, hospital, long-term care facility, emergency room, etc., must use electronic health records. However, even if all of a person's records are electronic, each such record is only a "slice" of the complete information.

Therefore, the second component is a way to use key elements of electronic information for a given person whenever and wherever needed for their medical care. This requires some type of communication mechanism among the various holders of electronic medical information. Together, these two components are known as "health information infrastructure."

Since the overwhelming majority of care received in a particular community is provided within that same community, the health information infrastructure is being approached as a community project. Many communities have recognized the potential value of health information exchange to solve the problem of delivering complete patient information when needed. While a few localities have made substantial progress toward this goal (e.g. Spokane and Bellingham, WA), there is as yet no statewide plan to provide a framework that will encourage similar community-based interoperability projects and create both an architecture for timely clinical data exchange accessible to all and a business model to support it.

III. Key Criteria for Solutions

The key criteria developed by the HIIAB to evaluate potential solutions include:

1. An agreed upon data set for each person should be available in a timely manner wherever it is needed. The scope of that data set and the speed of data exchange will be expected to increase over time.
2. Privacy, confidentiality, and security of medical information must be protected
3. Participation in the system should be voluntary and available to all.
4. Patients should be able to control who has access to any or all of their health records and see a list of all instances in which their information have been accessed by others.
5. Existing health information and health information exchange systems should be maximally leveraged to achieve the goals of interoperability.
6. Healthcare providers and institutions should be free to choose any electronic medical record system they wish as long as it communicates information using the agreed upon standards.
7. The data exchange solution adopted for the state of Washington should support electronic reporting required by law for public health and statewide clinical quality initiatives.
8. With patient permission, a set of non-identified health information of the community should be available for medical research and syndromic surveillance.
9. The system should be financially sustainable.

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IV. Status of HIIAB Deliberations on Approaches

The Board is currently considering several possible approaches to creating health information infrastructure for Washington State.

No specific approach adopted or endorsed. The HIIAB and HIISAC (Stakeholder Advisory Committee) will continue to seek input from stakeholders before making recommendations.

V. The Health Information Utility Model

A. Overview

The key premise of Health Information Utility Model is that each person's complete electronic health record (EHR) should be in one place where it can be readily available for use whenever and wherever needed. Since the EHR is very sensitive and private information, each person should be able to choose the organization, known as the Medical Record Home in which their information resides on their behalf. Furthermore, each person should totally control who has access to the parts of their EHR, including its possible use in non-identified form for medical research.

To implement such a system, a patient would identify a Medical Record Home. It would be completely at the patient's discretion to designate or transfer their electronic Medical Record Home. There would also be a method for authorized users outside that Medical Record Home to view key data elements from a person's EHR in real-time when authorized to do so; and by that person or someone designated by that person. Also, there would be a system to ensure that copies of new medical information are promptly deposited in each person's Medical Record Home so that it remains up-to-date and complete once established.

B. The Medical Record Home

A Medical Record Home is an organization that can maintain an electronic medical record for consumers. It is anticipated that in most cases this will be the healthcare delivery system or medical office in which that person receives their health care, but it could be a personal health record vendor or another type of entity that sees the opportunity to innovate and provide differentiated services. A Medical Record Home may choose to charge their patients a fee for this service.

A Medical Record Home would be responsible for maintaining an accurate, up to date, and as complete as possible copy of relevant clinical information for that person. Data obtained from other participating entities would be integrated and normalized into any internally generated data so that the combined information would be available to providers when the person was receiving care at their Medical Record Home. The Medical Record Home would implement policies and procedures to ensure 1) the privacy and confidentiality of the aggregated medical information, 2) the physical and electronic security of the data, and that the information is adequately backed up to prevent data loss in the event of a disaster or other emergency. A person could designate more than one entity as a Medical Record Home.

One example of an organization serving as a Medical Record Home would be a large multi-specialty clinic with a sophisticated electronic medical record system for its own patients. Another example would be a small clinic using an application service provider (ASP) EHR. In the latter case, although the clinical data for patients would not be physically kept within the physical boundaries of the clinic, the functionality of the data exchange would be the same.

There is no reason why patients could not choose to designate their Medical Record Home to be a Health Record Bank (see below) which would not be affiliated with any particular healthcare delivery system. It is assumed that a Health Record Bank would operate with a business model in which patients would pay a small monthly service charge to maintain their medical record, while the bank would pay healthcare delivery systems in which their clients receive medical services for clinical information pertaining to bank's clients.

Healthcare delivery systems and smaller clinics would have a choice as to how to finance the cost of this interoperability service. Some might assess small fees to individuals; others would not.

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C. Record Locator Service

To ensure that the Medical Record Home for an individual could be easily and quickly located by participating entities including non-Medical Record Home facilities, laboratories, pharmacy databases etc., there must be a Record Locator Service for the State of Washington that contains a set of demographic information on each individual, or a mapping table that associates a master patient index with local Medical Record Home indices, and identifies the Medical Record Home(s) for that individual.

This Record Locator Service would need to maintain electronic connections with all the entities registered as Medical Record Homes as well as all the sources of electronic medical information in the community. It would also need to be able to identify the Medical Record Home for each item of medical information it receives. The Record Locator Service would identify the location of read-only views available to providers from non-Medical Record Home facilities when a patient was seeking treatment at a non-Medical Record Home facility. The Record Locator Service would also notify the Medical Record Home that new data were available at a specified non-Medical Record Home facility and arrange for the transfer of those data to the Medical record home.

Financing for the Record Locator Service will be the topic of future HIIAB, sub-committee and stakeholder discussions.

D. Advantages and Disadvantages:

Advantages of the Medical Information Utility Model include:

1. The Record Locator Service is simple to operate, and therefore relatively inexpensive.
2. The Record Locator Service need not store any medical information whatsoever.
3. The clinical data for greatest value for each person's EHR would be immediately available when needed from their Medical Record Home.
4. Existing organizations with electronic medical record systems would be designated as Medical Record Homes. No transfer of clinical data to a new entity, database, bank etc would be required.
5. The Record Locator Service could serve the entire state, resulting in economies of scale (and a single communication channel for receiving all out-of-state medical information).
6. Individual communities would be free to develop their local health information infrastructure in whatever way they choose as long as there is:
 - a.) access to EHRs for members of their community; and
 - b.) a Medical Record Home where clinical information generated outside the community could be sent.

Disadvantages of the Medical Information Utility Model concept include:

1. A new community organization, the Record Locator Service, must be established (and funded).
2. Organizations must decide to be designated a Medical Record Home and:
 - a) provide a read-only view for their patient's records;
 - b) request, accept and integrate data for their patients when they receive care outside at a non-Medical Record Home facility;
 - c) export the agreed upon set of clinical data to the Medical Record Homes of patients who have designated another institutions as a Medical Record Home
3. State-of-the-art physical and computer security, privacy and confidentiality methods must be used to protect the data transfer between entities

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VI. Use Cases

1. An Entity signs up to participate.

An Edge Proxy Server (EPS) is set up for that entity. This involves several discrete steps. An interface is put in place through which an agreed upon transfer data set is maintained in a format making it accessible in read-only format when valid data requests are received. Data would be tagged with additional information (meta-data) that would identify the data source(s) and other necessary contextual information.

Inbound data from non-Medical Record Home or other Medical Record Home systems enter through the EPS where they will reside in clinical data system. Data normalization occurs at the EPS. The degree of integration and use of incoming data within the Home EHR will be left to the discretion of each entity.

Once it is operational, the EPS sends a patient identification resolution table message to the Record Locating Service (RLS) allowing the RLS to locate the records for that patient upon authorized request from another entity. The RLS resolves patient identity and creates/updates RLS patient id table that contains global id and all local id's. This is done through periodic update requests from the RLS to Home Edge Proxy Server.

2. Patient selects a Medical Home.

A patient presents at the facility of eligible health care provider that they want to act as custodian of their electronic medical record and completes an authorization protocol. The EPS of the entity to which the facility belongs then sends a home designation request message to RLS generating a response to the Home RLS. Home Edge Proxy Server sends update clinical data request to RLS. Periodic requests for updated information will pass between the RLS, the EPS and the production data base for the EHR of the Home entity.

3. Patient presents for care at a participating entity that is not their home (See Figures 1 and 2).

When a patient presents for care at a non-Medical Record Home facility without the intention of establishing that facility as a Medical Record Home, the patient authorizes the treating provider to access the read only view of their Medical Record Home clinical data. In an emergent situation in which the patient cannot communicate, known demographic data on the patient are assembled and if the Medical Record Home is unknown a probability match algorithm will be used to find the Medical Record Home for the patient. This method will not be expected to be as efficient as having the patient alert and cooperative. (A system of electronic medical alerts carried by the patient authorizing clinical staff in emergency facilities to gain access to the patient's data in an emergent situation could be developed.)

The treating providers (or designated support staff, use a web browser to request a view of the patients medical information from the RLS. At the RLS web site the requesting provider is authenticated (ideally through an existing OHP credential) and enters patient name and local identifier. The RLS sends request to the patient's Home EPS Server, which in turn delivers a view of the agreed upon data set to web browser. At the end of the interaction the RLS sends an email notification to patient that their information has been accessed documenting the viewer and the data viewed.

Figure 1
Patient Presents for Care
In Non-Medical Record Home Facility

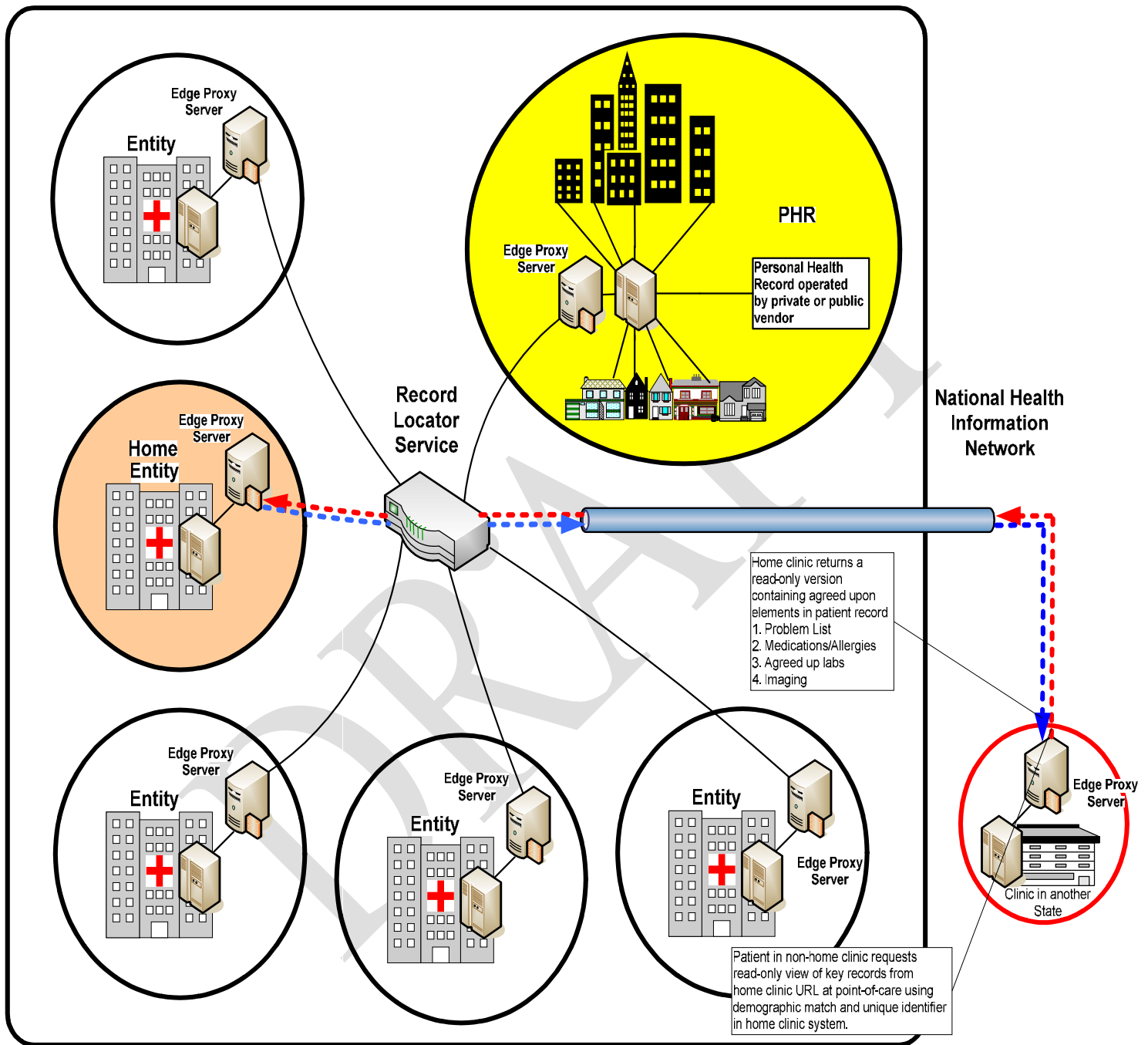
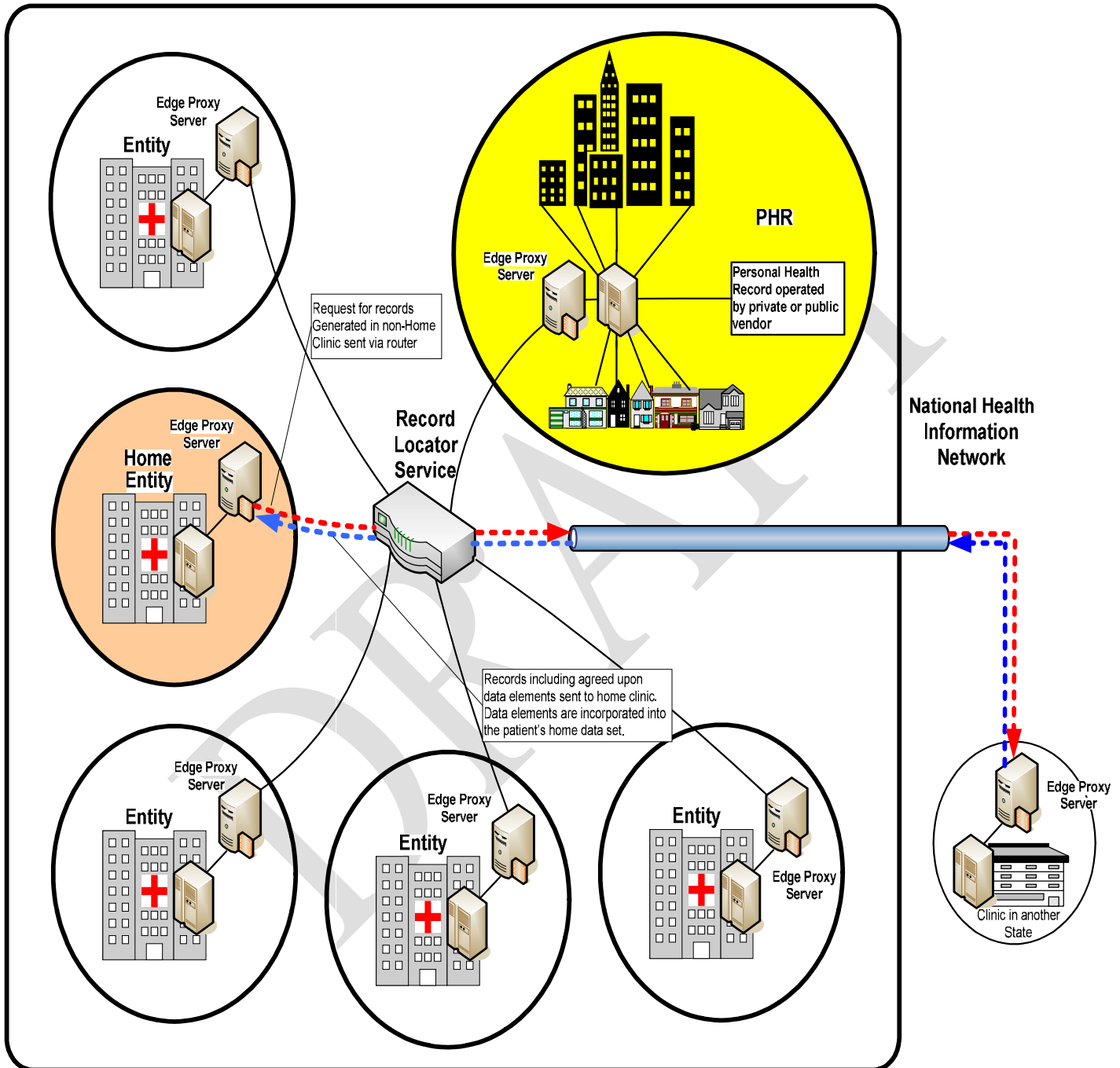


Figure 2
Data from Non-Medical Record Home Entity
Transferred to Medical Record Home.



V. Synopsis of Other Proposed Solutions

A full review of the alternative solutions is beyond the scope of this document. However, a brief synopsis of the other approaches is included to provide context.

A. E-Health Trust.

This is a system (see figure 3) proposed to the HIIAB by Dr. Bill Yasnoff, consultant to the HCA and HIIB on this project, also referred to as "Competitive Health Banking," in which each person would designate an organization of their choice, known as a Health Record Bank, to be the holder of their complete lifetime health record (LHR). Each LHR "account" would contain copies of all the electronic health information available for that person, and be available to medical care providers (via a secure Internet portal) only with the explicit consent of the account holder or their designee. Whenever new medical information about the person was produced, it would be encrypted and sent electronically to a community clearinghouse where it would be forwarded to the Health Record Bank holding that person's LHR so that it could be added to the existing information. All producers of medical information would send copies of all new records to a Community Clearinghouse to ensure the completeness of each person's LHR (as required by HIPAA). Each Health Record Bank would, for those account holders who consent, perform searches of their non-identified LHR information for public health agencies and authorized medical researchers.

To financially support these activities, Health Record Banks would assess small fees to individuals for maintaining accounts, offset by charges for access to the information for research purposes. As needed, Health Record Banks may also pay fees for deposits of information into individual accounts. To protect the account holders, Health Record Banks would be required to meet established criteria for privacy and confidentiality, security, backup, and governance.

The community clearinghouse (which could serve the entire state), would be a non-profit organization governed by a balanced group of health care stakeholders (including strong representation from consumers). The clearinghouse would support its operations by charging small transaction fees to the Health Record Banks for information sent to them.

B. Single Community Health Record Bank (or Centralized Data Repository) Model.

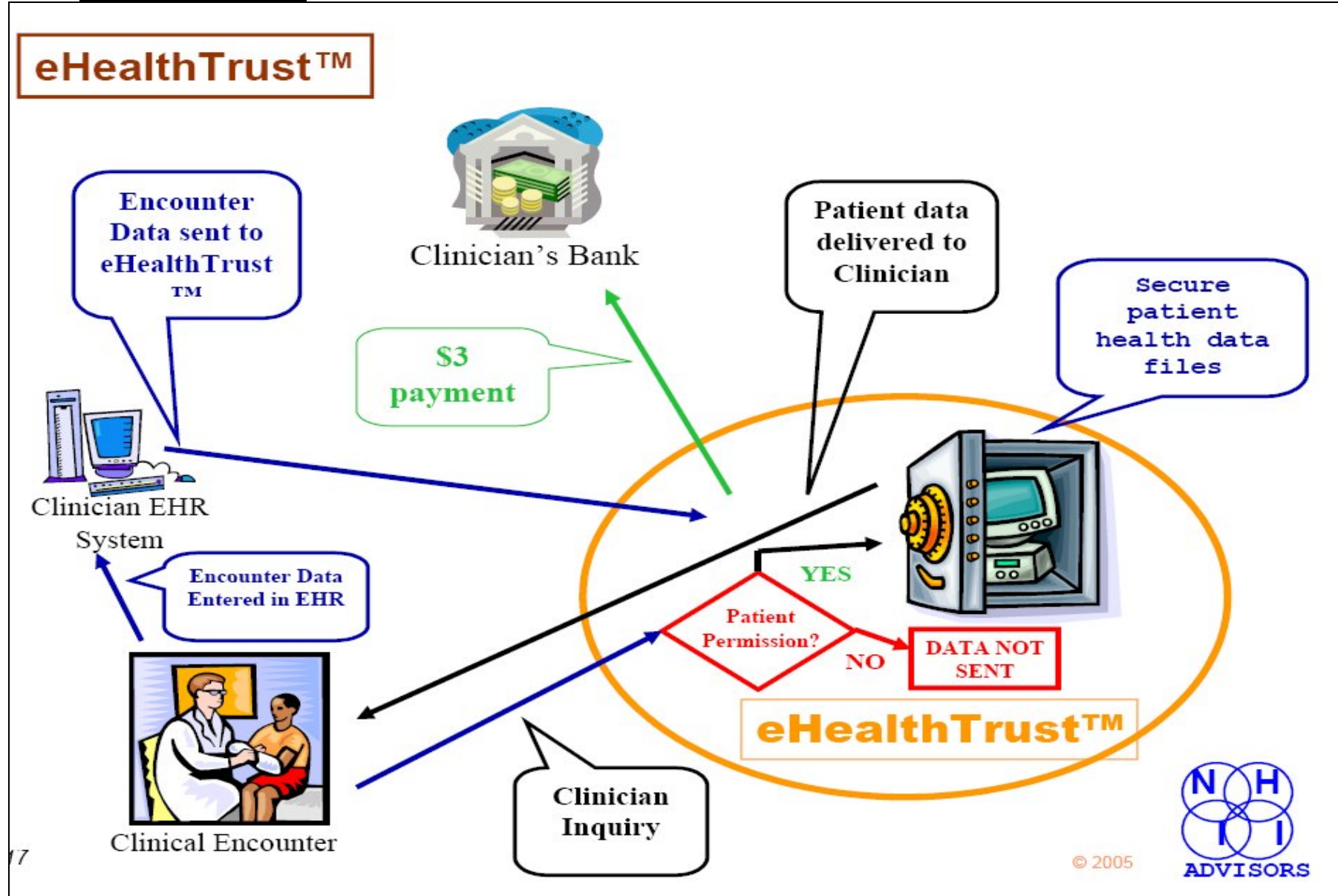
This model, (see figures 4 and 5) is a variation of the e-Health Trust/Competitive Health banking approach with a single Health Record Bank storing the LHR for each person in the entire community. To do this, the community must establish the Health Record Bank (to ensure its neutrality).

Since this single Health Record Bank receives all new medical information in the community, the Community Clearinghouse becomes unnecessary. As with the Community Clearinghouse, arrangements must be made with other communities to be sure that medical information for community members that is generated there is sent to the single Health Record Bank.

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Figure 3 eHealthTrust



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Figure 4 – Centralized Data Repository

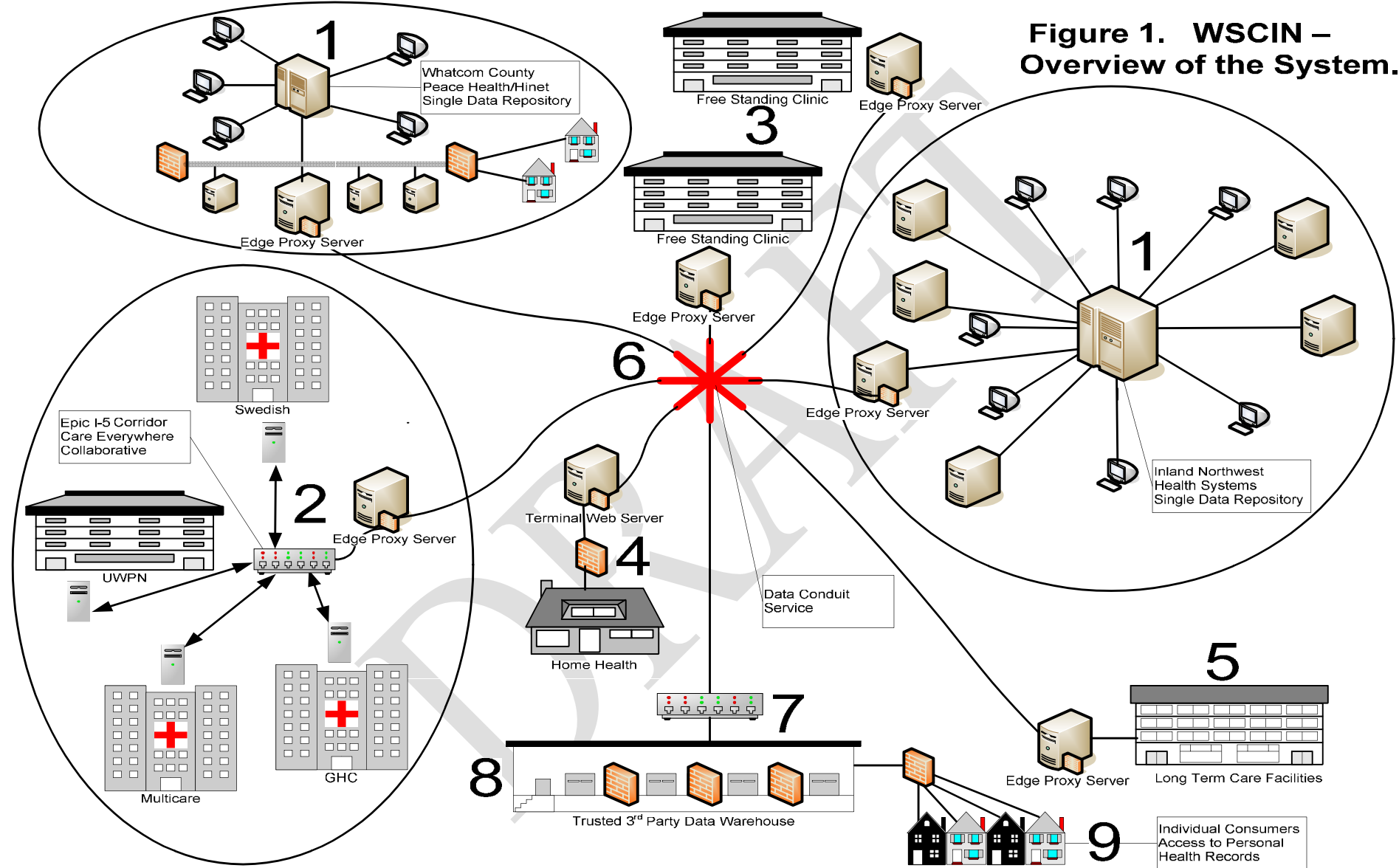


Figure 5 Centralized Data Repository Detail

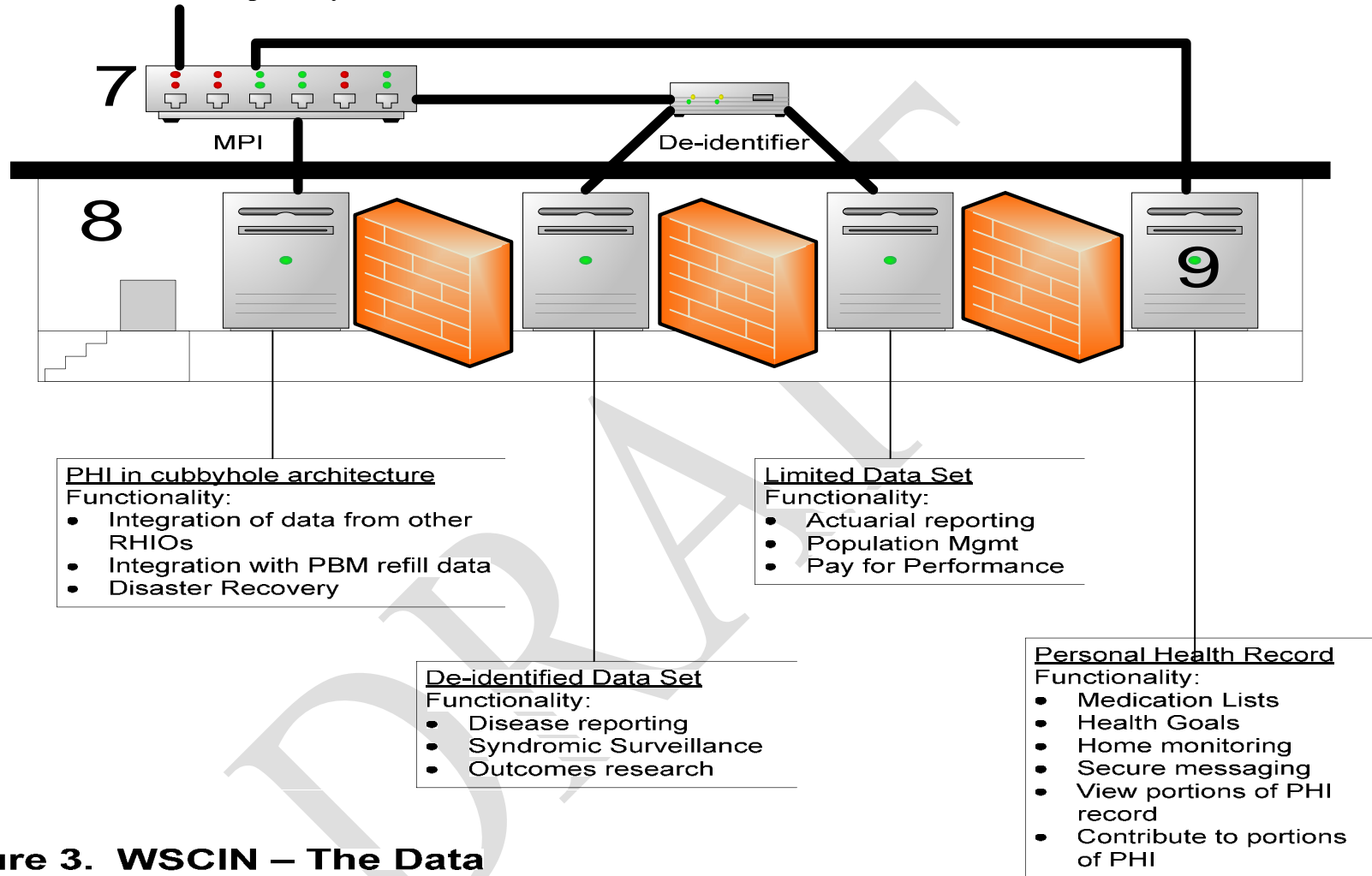


Figure 3. WSCIN – The Data Warehouse Structure and Function